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ABSTRACT

Provided are guidelines on administration, diagnosis, and treatment in federally funded EPSDT--Early and Periodic Screening, Diagnosis, and Treatment Programs, a system for providing health care services to Medicaid-eligible children. Detailed in part one are factors involved in developing EPSDT programs. Four chapters consider the need for EPSDT, available resources (including school health programs, neighborhood health centers and health maintenance organizations), organization of services (such as outreach workers and health aides), and fiscal and program evaluation aspects (including budget development, cost efficiency, and reimbursement). Part two focuses on diagnosis, treatment, and followup services in EPSDT. A chapter discusses diagnosis and management of problems such as vision and hearing impairment, growth and nutrition disorders, and developmental problems. (CL)

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A GUIDE TO ADMINISTRATION, DIAGNOSIS, AND TREATMENT

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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for the

Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT)

under

MEDICAID

by

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PREFACE

This guide to ADMINISTRATION, DIAGNOSIS AND TREATMENT prepared by the American Academy of Pediatrics is the follow-up to its "Guide to Screening - EPSDT Medicaid" published in 1974. Both guides are part of a series being developed on various components of the Early and Periodic Screening, Diagnosis and Treatment Program under Medicaid. Others already in print are "A Guide to Dental Care—EPSDT-Medicaid," by the American Society of Dentistry for Children and the American Academy of Pedodontics, and "A Report on Professional Health Provider Participation—EPSDT-Medicaid," by the American Medical Association's Committee on Health Care of the Poor. These materials are designed to be of help to those involved in implementing the program - State and local agencies and providers alike.

EPSDT is a unique opportunity for providing comprehensive health care to the more than 12 million Medicaid-eligible children. The partnership expressed in this collaborative effort between physicians, dentists and other health care providers, and government is a significant step toward the continuing coordination and cooperation so essential to the successful implementation of the EPSDT program.

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INTRODUCTION

In 1965, Congress enacted Title XIX of the Social Security Act (Medicaid) to increase the availability of medical care to persons who cannot afford it. It is a State administered program under which the Federal Government reimburses costs incurred by the States in providing medical care to low income individuals and families. The Federal Government pays from 50 to 78 percent of the costs incurred by the States, based on the per capita income of the State.

Medicaid recipients include persons and families receiving or entitled to receive cash assistance payments under the Social Security Act. In addition, States may elect to pay for medical care provided to medically needy persons and families (individuals whose income equals or exceeds the State's standards under the appropriate financial assistance plan but is insufficient to meet their medical costs). Each State determines the extent of services offered and the eligibility of recipients. As a minimum, to qualify for federal reimbursement under Medicaid, States must provide inpatient and outpatient hospital services, laboratory and x-ray services, skilled nursing home services, physicians' services, home health care services, and family planning services.

The 1967 amendments to Title XIX created the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. They added a requirement to Medicaid directing attention to the importance of preventive health services and early detection and treatment of disease in children eligible for medical assistance. The amendment requires State Medicaid programs to arrange for the screening of children under 21 years of age for physical and mental defects, and to provide the necessary health care to correct or ameliorate the defects. They further stipulated that treatment for visual, hearing, and dental defects must be provided.

EPSDT was to begin in 1971. Because of the complexities of initiating this program, interim regulations issued in December 1971 were superseded in June 1972 by Program Regulation Guide MSA PRG-21.[1] These regulations requested States to initiate EPSDT programs by February 7, 1972, for children under 6 years of age, and for all eligible children under 21 years of age by July 1, 1973.

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[1] *"Program Regulation Guide,"* MSA-PRG-21, Department of Health, Education and Welfare, Social and Rehabilitation Services, Washington, DC 20201, June 28, 1972.

Public Law 93-603 added a penalty provision effective July 1, 1974, requiring the Department of Health, Education, and Welfare to withhold 1% of a State's Title IV-A Aid for Dependent Children (AFDC) funds if a State (a) fails to inform the adults in AFDC families of the availability of child health screening services; (b) fails to actually provide or arrange for such services; or (c) fails to arrange for or refer to appropriate corrective treatment those children identified by such screening as suffering illness or impairment.

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PART ONE: DEVELOPMENT OF EPSDT PROGRAMS

CHAPTER 1

THE NEED FOR EPSDT

Importance of the Program

A person who is born into poverty and dependence on welfare and never escapes from it represents a waste of human potential and a drain on the resources of the country. From a financial standpoint, the person who remains on welfare from birth until the age of 65 may cost the taxpayers at least $200,000 in direct support. When the indirect costs of social services and other supportive activities are added to the loss in income taxes not paid by welfare recipients, the total cost reaches astronomical figures. Therefore, it seems advisable to invest in those services which show promise of enabling needy and disadvantaged children to grow into productive adults.

Although not the only requisite for the development of a productive adult, good health is a basic factor. Poverty and health status are intimately related. Untreated health defects lead to dependency and, in turn, to the perpetuation of the welfare cycle.

Early and periodic screening, diagnosis, and treatment introduces eligible children into the health care system; makes services available before health problems become chronic and expensive to treat; and increases the chances that eligible children can become productive members of society in adulthood - contributing workers in the labor force and independent of public assistance programs.

Why Some Children Do Not Receive Good Health Care

The most obvious barrier to the delivery of a reasonable level of health care is the unavailability of resources in the community. There are areas, particularly rural, that do not have adequate medical resources for anyone. Communities which have moderate resources may make these services available to the well-to-do but not to the needy.

Even in communities with adequate health service resources, there are barriers which prevent the needy child from receiving health care. Many

barriers are inherent in the child's socio-economic situation. A family struggling to survive at a subsistence level usually gives health care a low priority, except in time of medical crisis.

Cultural barriers also interfere with obtaining health care. For example, people from some cultures go to faith healers for care and to medical resources only at time of acute illness, if at all. When the patient speaks a language different from that of the local society, he[2] will have difficulty using the system.

Another barrier is limited to excessive mobility. Some migrants never stay in one place long enough for their children to receive continuous health care. Conversely, in many cities the poor tend to stay locked in their neighborhoods. They are unable to leave because they do not understand the language, cannot afford transportation, or because they regard a particular neighborhood as "their turf" and anything beyond it as a danger area.

Some health care providers are not willing to see needy patients, and justify their unwillingness to do so on inadequate or late payments and/or the extra time and effort required to deal with seemingly unappreciative patients of a different culture.

Even physicians willing to see needy patients sometime encounter difficulties which seem impossible to overcome. The physician may find that Medicaid patients do not keep appointments or are unable to come to his office. No matter what the reasons, the physician who allots 1½ hours for a Medicaid family of three or four which does not keep the appointment suffers financial loss. The physician who is willing to see patients from poor areas and even moves his office to do so, may be faced with the frustrating problem of trying to deliver care to patients with whom it is difficult, or impossible, to communicate.

Provision of Care for Medicaid-Eligible Children

For the first time, State Medicaid Agencies have been made responsible for assuring that appropriate care is available, and that people are helped to utilize it, rather than just pay for it. This change in responsibility has created a new area of activity for these agencies. Medicaid, previously a vendor-payment program, now has to assure the availability, accessibility, continuity and help in effective utilization of health care services for EPSDT eligible children and youth.

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[2]For brevity, either "he" or "she" is used throughout this document; however, the word used is intended to apply equally to both sexes.

EPSDT services include periodic examinations; an assessment of dental, nutritional and developmental health status; blood tests for the detection of anemia, undue lead absorption, and sickle cell disease; assessment of vision and hearing; and tests for urinary infection and tuberculin activity. Defects identified are to be corrected or referred for diagnosis and treatment. Immunizations appropriate to the age of the child are given if not already received. EPSDT is more than screening; it also includes diagnosis, treatment, and health maintenance as part of continuous and comprehensive health care.

Special Problems in the Diagnosis and Treatment of Medicaid-Eligible Children.

Efforts to bring children eligible for Medicaid into care needs the active support and participation of the professional community. The effective delivery of health care can best be achieved when the provider is sensitive to the patient's cultural, social, ethnic background. When the provider and the patient have different backgrounds, success in obtaining patient cooperation depends on the provider's intelligent and thoughtful accommodation to the cultural, social, and ethnic differences that present themselves.

Many health providers work with people in the community who can act as a bridge between patients and health professionals. In addition to bringing the patient to medical care, outreach workers, often referred to as health aides, may also be needed to interpret, to act as the patient's advocate, and to help the patient understand and effectively use treatment. This person can also facilitate follow-up to ensure continuity of care. Without proper follow-up, the best of care may be ineffective.

An example may be found in the following story:

> In the fall of 1968, in anticipation of the establishment of the South End Community Health Center in Boston, a medical screening program was held for neighborhood children going to summer camp. At that time there were no private pediatricians in this inner-city community, and nearby hospitals were unwilling to accept well children for routine health examinations.
>
> Nearly 2,000 children were examined in a 2-month period in a collaborative community program. One of the screeners was surprised to discover an 8-year-old boy, J.G., with a severe cleft palate. J.G.'s parents were well aware of his problem and had no objection to his referral to a hospital specialty clinic. The appointment was made but not kept. A

health aide then made a home visit. She learned that, although Mr. and Mrs. G. understood the nature of the problem, they were frightened by surgery because another family member had died after surgery in a hospital.

Another home visit was made by a health aide with the same background as the family. She explained with understanding and sympathy what was recommended and why it was important for J.G.'s speech, hearing, and future life that his cleft palate be repaired. The worker personally brought the family to the speciality clinic, stayed with them, and explained again what was needed. The family agreed to the surgery. On the day of admission, the health aide accompanied them to the hospital. She continued her support until J.G.'s cleft was repaired, he was discharged, and he was enrolled in speech therapy.

Another example of sensitivity to a family's needs and perceptions is understanding why some families with strong orientation to their ethnic or racial backgrounds will not follow advice on medication, or change their infants' feeding habits. They believe in the "hot and cold" theory of disease and treatment. This philosophy, which may be related to the ancient Oriental belief in opposites, yin and yang, ascribes hot or cold qualities to many diseases, foods, and medication.

"Hot" disease, such as febrile illnesses, need treatment with "cold" remedies such as penicillen, hence a demand for antibiotics. According to the theory, vomiting in infancy is another "hot" disease and should not be treated by feeding the baby formula (which is "hot"), but by whole milk (which is "cold"). Therefore, many babies who spit up formula are switched to regular milk, with harmful effect. It takes years, even generations, to change and bring best medical practice to some families who will accept change only when they have developed trust in their medical providers.

Some patients are not literate. Therefore, advice and treatment need to be explained in simple terms and repeated until understood. This also means that as few medications as possible, consistent with good care, should be prescribed; and dosage schedules should be kept as simple as possible. Follow-up is vital and if, for example, the patient is not taking the prescribed oral penicillen, consideration should be given to long-acting intramuscular injections as the most effective method of treatment.

Health providers need to understand how their patients live so they can intervene effectively. Children with infected mosquito bites need to be given medication for bites; in addition, window screens need to be installed. The treatment for rat bites only with tetanus toxoid and penicillen, without effort to eradicate the rats, is another example of attacking the symptom and not the cause.

Nutritional problems need to be fully understood. If iron supplements are the only treatment given for iron-deficiency anemia, the anemia will only be partially and temporarily treated. The general nutrition of a patient also needs to be improved. However, the family may not have enough money to buy proper foods and/or they may not know how to obtain and use surplus foods unless they have assistance. In many areas, programs may provide not only nutritional supplements, but also nutrition and health education, which are important components of health-related supportive services.

Child Abuse and Neglect

Poverty is not the only cause of child abuse and neglect, but it is an important factor contributing to family stress. A family on welfare does not have the money for baby sitters, transportation, and other services which can ease the burden of overcrowding, pressures, and the constant demands of small children.

If the potential for abuse or neglect is present, the stresses of poverty may precipitate its occurrence. The overwhelmed mother may be unable to cope unless she receives help. Timely help can only be supplied if the need is identified and supportive services intervene before a child is injured.

Criteria should be established for identifying socially high-risk mothers during pregnancy as a possible means of preventing future child abuse. The unwed teenager with an unwanted pregnancy, the expectant mother who denies her pregnancy, and parents who were themselves abused as children are all potential child abusers. An isolated, severely depressed mother may find the first few weeks with a new baby an intolerable burden. Drug abuse and alcoholism in a family may place a child at severe risk. Other possible indicators of high-risk children are:

— previous abuse or neglect
— a child failing to thrive without apparent reason
— repeated minor injuries or poisoning
— extremely poor appointment-keeping

Intervention depends on the effective use of medical and health-related supportive services in the community. The discovered need for presently unavailable resources may begin to encourage communities to develop needed services.

CHAPTER 2
RESOURCES

Identification and Organization

EPSDT should be implemented wherever possible by coordinating or integrating existing resources into current program, rather than by setting up separate new systems. Fragmented resources can become the nucleus of a comprehensive EPSDT program if the resources are effectively organized and augmented. Where resources do not exist, however, they should be developed.

Following are some resources that may be found in a community:

- a public health department performing specialized screening such as for tuberculosis, venereal disease, vision, hearing, and undue lead absorption
- state laboratories
- a health department's well baby clinics and crippled children's clinics
- a hospital providing 24-hour emergency care, speciality clinics, and newborn nurseries
- a neighborhood health center
- a school health program
- a visiting nurse association
- a home health care program
- private practitioners

Expansion of Limited Resources

The capabilities of a particular limited resource can be expanded. A well baby clinic or a school health program can be used as a base which, by the addition of other resources, can become a comprehensive care provider.

A public health clinic augmented by the services of a school physician is another example of a potential comprehensive care center. Conversely, the

physician in solo practice can increase his care-giving capabilities by the effective use of pediatric nurse practitioners and other non-physician personnel.

School Health Programs

One of the challenges of delivering health care to the needy is to make the best use of school health programs, since schools provide a concentration of school-age children. Immunizations and screening for such conditions as hearing, visual defects, and tuberculosis can be provided in the schools. However, inadequate physical examinations on multitudes of children by a school physician, with no history or input from parents, are of little value.

Depending on the circumstances, school health programs can be used as the basis for comprehensive care programs, or a comprehensive care program can also provide the required school health services. In a rural area with limited health care resources, it is advantageous to use the transportation provided by the school bus and the resources committed by law to school health programs as essential ingredients in a local EPSDT program.

Since the most important years of preventive care occur between birth and school age, additional effort would have to be made to reach preschool children if an EPSDT or comprehensive health care program were built around the school. A preferable approach is when the health care provider takes basic responsibility for comprehensive and ongoing care of a child. This might mean that the school would purchase services from a comprehensive health care provider rather than hire its own school nurses and physicians.

State Health Agencies

State health departments are often fragmented according to disease or function rather than organized for comprehensive care. In some States, public health departments and Title V (Maternal and Child Health) programs may be the best available system for implementing the EPSDT program. If a State's health department is given the responsibility for the delivery of EPSDT, it should be organized to facilitate the delivery of comprehensive health care.

Head Start

Head Start is a preschool program for children from families with low income. In many communities the health component of Head Start has developed expertise in how to obtain health care for children. Some of the goals of the Head Start health component and EPSDT are similar: to identify and provide for the treatment of health problems as early as possible, to introduce a child into a continuous source of medical care, and to encourage the preventive aspects of medical and dental care.

Head Start programs help families find sources of medical care. In some situations where health care has been unavailable or inaccessible, arrangements have been made to transport children to the source of care or to bring health professionals to the children.

Every Head Start program has developed its own health advisory committee. Systems have been set up so program administrators, health professionals, and parents can define problems and work together to resolve them.

The American Academy of Pediatrics has worked with the Office of Child Development to provide technical assistance programs with experienced consultants in health and administrative fields. Standard setting and evaluation procedures have been developed to assess programs.

In 1974, the Office of Child Development, in close collaboration with the Medical Services Administration, lauched a major effort in approximately 200 Head Start programs to assist in making EPSDT services available to Medicaid-eligible children between ages 0-6. The objective of this project was to demonstrate replicable approaches for bringing about local collaboration among Head Start programs, State and local Medicaid agencies, and community health and related resources in the delivery of EPSDT program services. Since many Head Start children are not currently enrolled in Medicaid, but are probably eligible, effort is being made by Head Start to obtain coverage under Medicaid for needed health care services for these children and to enable such children to benefit from the State's EPSDT program provisions.

Private Physicians

The efficacy of private physicians in delivering care to Medicaid-eligible patients may be enhanced by:

- having a bilingual receptionist in a foreign-speaking community
- developing a capacity for seeing walk-in patients through the addition of a pediatric nurse practitioner or allied health professional

— confirming appointments by telephone calls or post cards to help prevent missed appointments
— spending time in a neighborhood health center, a public health clinic, or other EPSDT screening site

Community nursing is a major support for both the physician and the patient. Health education, nutrition education, transportation, follow-up counseling, and other health related supportive services are also necessary functions for both the physician and the patient.

Many supportive services are necessary when problems beyond the scope of the physician's usual activities are detected. For example, transportation may be needed and health education might be helpful. Or the physician who detects lead poisoning cannot be expected to go into the home and repaint it, nor can he act as the lawyer or the social worker when a child is abused. However, the physician may be the advocate and catalyst for action by other community services.

At another level, the physician can play a major role in shaping and supporting programs by participating in the activities of the local professional societies and government.

Hospitals

Patients do not usually receive continuous or comprehensive care in hospitals. Most hospitals are equipped and staffed to deal primarily with emergencies or special problems. However, hospitals may fill the gap in the primary health care system for many patients, particularly the poor. While hospitals may not be the ideal setting for delivery of comprehensive care, they can play an important role in the delivery of EPSDT in many communities. By establishing new policies and procedures they can adapt services to deliver EPSDT to children who have no other source of care. With adequate fee schedules, such services could be a source of added income to the hospital.

An emergency or outpatient department can—by developing a service staffed with physicians and pediatric nurse practitioners—deliver screening, treatment, and referral care. Specialty clinics can maintain standards that include questioning for health and immunization status of all patients and carrying out appropriate screening tests for anemia, undue lead absorption, and urinary tract infections.

Comprehensive health evaluations can be carried out on children admitted as inpatients for other reasons. For example, a child on an orthopedic ward with a fracture can receive vision and hearing or other EPSDT procedures while the fracture heals.

A useful technique to remind personnel in hospitals using problem-oriented records about EPSDT can be to regard problem #1 as routine health maintenance. This emphasizes the importance of first considering routine health maintenance for any child, irrespective of the presenting of other medical problems.

Referrals

If the hospital is used as a referral center by physicians or other health care providers in the community, EPSDT out-reach programs can be an essential part of the referral services.

Hospitals can also establish their own resource for primary care referrals by having a physicians' building associated with the hospital or by establishing a health facility similar to a neighborhood health center. Such a decision should be made only after consideration of the existing primary care resources in the community.

One of the most important sources of referral is the newborn nursery. The newborn infant receives careful examinations at birth and in the first few days of life. Referral to a source of continued care in the community should be made by the nursing staff, who will be familiar with those resources. The physician who is to provide the ongoing infant health supervision should see the mother and child for the first time before discharge from the nursery. This is especially feasible where the community physicians are attending staff members of the hospital.

Mothers may be most receptive to health education and counseling on health care during the first days of an infant's life. The hospital staff should use this opportunity to discuss the importance of well child supervision after discharge from the hospital, and the mother should be told where she can obtain the necessary medical services. The nursing staff at army hospitals has developed liaison with public health nurses in the community who can follow-up to ensure that referrals to community medical resources are completed. Family planning clinics can provide EPSDT services for older children.

Neighborhood Health Centers

Many low-income communities have neighborhood health centers. These community-based facilities were established by a variety of funding

sources, including Model Cities; Office of Economic Opportunity; the Children's Bureau; Public Health Service 314 (e) funds; and, in some instances, sophisticated and innovative use of Medicaid. Many States and cities make their own contributions in support of neighborhood health centers. These centers attempt to fill a major void in the primary health care system.

An effective neighborhood health center is more than a well child clinic or an emergency service. The health center staff provides comprehensive health care. The staff usually is bilingual; and outreach, transportation, follow-up, health education, and other health related supportive services are provided. Medical care is provided by physicians aided by nurse practitioners and other allied health personnel. As with any primary care provider, referral resources are established for subspecialty services and hospitalization. A neighborhood health center can tailor its services to meet the needs of the community. Because it is part of the community, it is convenient for the patients and preventive care is easily delivered.

As neighborhood health centers become increasingly less dependent on Federal grant funding and increasingly more dependent on third party payments such as Medicaid, Medicare, or national health insurance, States will begin to make increased use of these facilities for provision of care to Medicaid-eligible clients.

Health Maintenance Organizations

The health maintenance organization (HMO) is an organized system of health care that guarantees to provide quality physicians' services, emergency and preventive care, and hospital services when they are needed to individuals and families who have voluntarily agreed to obtain their medical care from the HMO for an extended period of time, in return for payment (generally by the month) of a fixed sum of money, agreed upon in advance. HMO's vary from the structured organization of the prototype, the Kaiser-Permanente Health Plan founded in 1938, in which physicians work out of single sites such as group practices and have a working organizational relationship with a hospital; to systems oriented organizations in which provider members function together in delivering medical care while continuing to be paid individually on a fee-for-service basis, and working out of their own offices.

Health maintenance organizations, like neighborhood health centers, can be an ideal vehicle for EPSDT. They share the common elements of preventive, comprehensive, and continuing health care made accessible to the poor through arrangements with State and local Medicaid units.

Dental Services

Since infected teeth can create the same problems as any other general infection can, dentistry should be an integrated part of the total approach to the prevention of disease and disability and the provision of remedial treatment, with the ultimate objective being total health for the child.[3]

Dental caries are the most frequently found health problem in children. The main dental need in an EPSDT program is arrangement for services rather than screening for problems. Referral mechanisms should be set up on the basis that the referral rate will be almost 100% since most children need dental care.

Most States have limited Medicaid dental care to relief of pain and oral surgery. Under EPSDT dental care is a required service for those under 21, although the scope of dental care provided still varies in the different States.

There are analogies between dental care and medical care. The preventive nature of fluoridation and prophylaxis is similar to immunization, and restorative and curative dentistry also have their medical counterparts. As in medicine, the patient with an acute dental problem is more likely to come for care than he would for preventive treatment. However, there is substantial difference in periodicity between medical and dental care. Fewer medical visits are usually recommended as the child grows older; however, the number of dental visits recommended remains fairly constant.

Low-cost dental kits with instructions for their use can be obtained from toothpaste and toothbrush manufacturers. The need for regular dental care and preventive services must be stressed.

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[3] "A Guide to Dental Care, EPSDT-Medicaid" SRS/HEW in cooperation with The American Society of Dentistry for Children and The American Academy of Pedodontics, Washington, D.C. 1975.

CHAPTER 3

ORGANIZATION OF SERVICES

Considering the wide variety of resources identified in Chapter 2, the way in which EPSDT services are organized may vary considerably. A provider of comprehensive care - such as a pediatrician, family practitioner, neighborhood health center, or health maintenance organization - can facilitate the delivery of screening, diagnosis and treatment by delivering all of these services at the same time and in the same place. The comprehensive care provider can do the following:

1. Be sensitive to health needs which go beyond the "well baby/sick baby" concept. Developmental, mental health, family relationships, and sexuality are as integral a part of a child's health as throat cultures and tuberculin tests.
2. Know the patient so communication is beneficial to all parties.
3. Draw on a variety of other resources in the community, such as specialists, hospitals, and other supportive services.

If enough comprehensive care providers are not available, a program of screening, diagnosis, and treatment must be organized from the component parts to deliver proper care to children.

Many children now receive care from a variety of fragmented resources such as well baby clinics, school and preschool health programs, crippled children services, immunization programs, public health and visiting nurse programs, and hospital emergency and outpatient clinics. Linkages must be developed between these resources so the child can be screened periodically and problems diagnosed and treated. High-risk children who need the benefit of a one-provider, comprehensive care program might be identified by this process.

Responsibility for Care

In many States the major responsibility for organizing and delivering health care to the poor will rest with the county and local government rather than with the State government.

Local and county units have an advantage over larger governmental units in that they have an opportunity to know community resources and the needs of their clients.

A lead agency with sufficient responsibility and authority to ensure that the EPSDT mandate is carried out must be designated. A coordinator or coordinating committee does not have the authority to resolve the problems of combining the resources of separate departments of health and welfare providing or purchasing services, or both. The attempt to coordinate various parts of government in some States is often formalized with interagency contracts. However, interagency contracts are usually not binding adequately to ensure coordination and cooperation. An EPSDT program can succeed best if final decisions are made by someone with authority over all of the participants in the delivery program.

Responsive and responsible people must represent the State to the health care community. If those in State government are unable to communicate with the medical professionals or are unable to understand their viewpoints and problems, the State's program will have problems. Representatives of the medical profession should be involved in advisory and consultation capacities at all stages of planning, as well as in implementation.

The lead person should bring together an advisory group which includes representatives of the governmental and private sectors. This group might include representatives of the American Academy of Pediatrics, the American Academy of Family Physicians, the American Association of Ophthalmology, the local medical, dental and optometric societies, visiting nurses, Head Start; and school health programs. Participation by such organizations will assist in developing and implementing a workable program.

The resources and conditions vary considerably within individual States; the problems of New York City and Cleveland are not the same as those of upstate New York or downstate Ohio. Therefore, a State's policies should encourage local responses to local needs. Local and county units with resources for the delivery of health care and outreach should make judicious use of their resources. EPSDT provides an opportunity to reorganize their resources and upgrade the level of care they can provide. EPSDT may also be used to upgrade the Medicaid system in States where the program's services cover less than provided for under EPSDT.

Setting up the Program

The State, county, and local health care resources should be evaluated to determine whether screening, diagnosis, and treatment will be delivered by those who can provide the entire program themselves. If not, it will be

necessary to organize and coordinate separate programs, each delivering some part of screening, diagnosis, and treatment.

There is a broad range of training and expertise within the health care profession, extending from various kinds of health aides to physicians.[4] If physicians are available only for referrals or as consultants, it will be necessary to develop a program in which nurses and allied health professionals will be responsible for screening. This system might generate referrals that would not be necessary if a physician were present. If screening is separate from diagnosis and treatment, there is concern that a child may pass through the screening program with every indication of normalcy and yet have problems that the screening did not have the sophistication to recognize.

An appropriately educated pediatric nurse practitioner (PNP) working with, and under the supervision of, a physician has the capability of conducting an adequate screening program. A program which appropriately uses the PNP and has a physician available to see patients may be approaching the provision of comprehensive care, depending on its ability to maintain continuity of services.

The following models demonstrate different variations in the activities and interaction of the health aide, nurse and physician.

Model One: The Health Aide with Supervision of a Registered Nurse.

A health aide can administer screening tests in the absence of a physician, or nurse, if there are clear guidelines for performance of the tests. Over-referral and screening errors can be kept to a minimum if good nursing supervision and physician consultation are available. Good communication must be established with other resources to enable children with problems to receive appropriate examinations, confirmatory tests, and treatment. Immunizations and other treatment can be given under the standing orders of a physician.

A health aide, after training and under the supervision of a nurse or physician, can do the following:

1. administer a health questionnaire, including immunization status
2. make home visits when appropriate
3. collect blood by finger stick for hematocrit, erothrocyte protoporphyrin, blood lead, or sickle test

[4] *Allied Health Workers in Pediatric Practice*. Office of Allied Health Manpower, American Academy of Pediatrics, P.O. Box 1034, Evanston, Illinois 60204, October 1974, defines the qualifications of the various levels of these workers.

4. perform an hematocrit and sickledex test
5. perform uninalysis by dipstix, obtain clean catch urine for culture, and obtain a stool sample for parasite studies
6. perform and read a tuberculin test
7. perform basic tests for visual acuity and hearing
8. administer a simple developmental screening test
9. measure and record height, weight, head circumference and blood pressure
10. provide health education

Model Two: The Pediatric Nurse Practitioner.

A pediatric nurse practitioner - with appropriate physician supervision - can perform screening services, make comprehensive assessments, and diagnose and provide treatment. The responsible physician may develop a protocol with the nurse practitioner for the diagnosis and treatment of specific conditions. The ability of a pediatric nurse practitioner to provide health care services far surpasses that of a nurse who has not had special training in the care of children.

The following may be included in the protocol:

1. diagnosis and management of streptococcal pharyngitis, impetigo, otitis media, and respiratory tract infections
2. diagnosis and treatment of parasitic infections
3. diagnosis and primary treatment of iron-deficiency anemia
4. diagnosis and treatment of simple, acute gastroenteritis
5. counseling in sickle cell disease
6. identification and appropriate referral of heart murmurs, hernias, and other physical abnormalities
7. management of nutritional problems
8. identification of emotional, developmental, and other disorders

Model Three: The Physician.

A program which has substantial physician involvement can provide EPSDT with a minimum of referral. Programs, however, can function at less than maximum effectiveness when the professionals are not used properly. It is important that the physician does not do what a nurse practitioner can do, the nurse practitioner does not do what a nurse can do, the nurse does not do what a health aide can do, and the health aide does not do what a clerk can do.

Outreach

The EPSDT mandate does not allow a State to limit its activities to making services available. It must ensure the delivery of care. To make people aware of the services available and to bring them into the delivery system requires outreach. Outreach is the bridge between the provider of medical care services and the recipient.

The poor have difficulty in seeking and obtaining medical care and in using it effectively. They may have little or no experience in organizational life, and are insecure in the middle class world. They are especially vulnerable to the impersonalization of massive, medical organizations and large buildings; complexity and bureaucracy lead to an unfriendly and impersonal atmosphere. The poor do not know how, nor do they have the resources, to cope with the system; and, they seldom have anyone to help smooth their path.

The poor learn to deal with the frequent crises they face. They are generally uninformed about illness and seek treatment only when practically forced to it. Symptoms that do not incapacitate are often ignored. The poor are generally skeptical about the value of prevention and early sickness care, and seek treatment relatively late in a disease. Many have little understanding of how to carry out prescribed treatment.

The development and use of *outreach* — identifying and informing eligible children and youth about EPSDT -- and *health support services* — arranging for the availability and accessibility of EPSDT services, assisting in their effective utilization, and maintaining an ongoing relationship between the child and the health care provider — are significant and meaningful aspects of community health programs.

Outreach plans range from those designed to reach large numbers of children to those designed to identify and reach the most isolated and/or highest risk children. Health support services include health education, case management, transportation where needed, and advocacy. These services can help some patients who need help in persisting through the administrative maize in obtaining needed treatment. They can be helpful to others who may have problems in obtaining or paying for transportation to the source of medical care, in arranging for child care services, in following through on prenatal care, and in pursuing preventive care for their children.

To aid States in the development of effective outreach and health support services, the Medical Services Administration has made available 75% FFP (Federal financial participation) under Title XIX for staff providing such services under medical supervision.

Outreach Workers and Health Aides

The key to successful program outcome is involvement of the patient with an outreach worker or health aide. This worker usually lives in the community. He knows the problems that exist, and can best relate to the needs of the population. He is a friend and advocate of the patient because he knows the neighborhood and the people who live there. His earlier years have prepared him to understand, empathize, and communicate patient needs to the professional worker.

This worker helps to bridge the cultural gap between patients, professional staff, and the community; improves communication between these groups; and assists in the effective delivery of health care to patients and their families. The outreach worker/health aide is an important component of the health care team.

Outreach workers and health aides usually are under the supervision of a professional staff member of the health team. They are trained to perform a variety of activities based on their capabilities and the needs of the community. Some of these activities are:

- providing information on health and health-related problems, including case finding in the community
- informing Medicaid-eligible community residents of available medical and health services
- assisting in the development and use of health educational materials in language and cultural context that is understood
- helping to demonstrate how to prepare and serve nutritious meals using acceptable and economical foods
- assisting patients in following therapeutic regimens recommended
- assisting families in obtaining and keeping appointments
- conducting follow-up visits in homes
- participating in community and health care team discussions

Media

The easiest way to acquaint large numbers of people with EPSDT is through "shotgun" techniques which inform them of their entitlements but leave the responsibility of seeking care to them. An announcement can be made through newspaper, television, and radio stating that an EPSDT program is available at no cost for Medicaid eligible children. Information

about EPSDT can also be included in monthly assistance checks. This information should be in a language that is used by the Medicaid population. A pamphlet explaining EPSDT is also useful. However, all of these "informing" techniques are less effective than personal contact by an outreach worker in informing parents of eligible children and assisting in arranging for their active involvement in EPSDT services.

Use of the AFDC System

Another technique is to make an EPSDT referral a requirement in the welfare eligibility and redetermination process. The welfare department intake worker is in a position to inquire whether the children are currently under medical care supervision; if they are not, the worker should have a resource list and make an appointment immediately if there is no identifiable EPSDT unit available to carry this responsibility. However, this approach puts a major burden on social workers who may be fully extended already.

Transportation

In areas with few health care resources, it may be necessary to bring services to the child through the use of mobile units, nurse home visits, paramedical personnel making rounds, or local clinics staffed on a periodic basis. The problem with bringing the care to the child is that the professional provider must spend a considerable amount of time traveling rather than providing care; therefore, it is more efficient to use allied health personnel to do the traveling for screening purposes.

Management of Referrals

There are three major bases for referral. One is for a problem beyond the diagnostic and care-giving potential of the screener. Another is to get the child into ongoing care. The third is the need for care by a specialist.

Every local EPSDT program should establish guidelines for referral and should have prearranged referral resources. The physician, however, determines the need for referral in individual cases. The physician should be responsible for training the screening personnel and monitoring their activities. He also should establish the levels of problem intensity which indicate the need for a retest or a referral, such as levels of hemoglobin or hematocrit, and results of urinalysis, vision, or hearing screenings.

Physicians who provide primary care to children generally do not perform surgery, do not do refraction, and usually do not have the capability of managing complicated cardiologic, orthopedic, neurologic, or metabolic problems. Decisions on referrals are made by these physicians to hospitals or specialists in their community.

The public health department or building departments should be notified to initiate lead hazard identification and reduction services for children identified with undue lead absorption. The specialty services performed by the epidemiologist and environmental health personnel are generally available from public health or building departments. Without their assistance, the afflicted child will be reexposed to the lead hazards and increase the risk of permanent neurologic damage.

The following procedures are suggested in making a referral:

1. A source for the referral care has to be identified and an appointment made. If there is no specialist in the immediate area, the person making the referral must decide whether the condition warrants a difficult, long-distance referral, or whether the problem can be dealt with in another way, perhaps by a telephone call.
2. A letter of referral from the screener should be sent to the referral center. This letter should include all information necessary for the provider to give the appropriate care. The name of the Medicaid card holder and the Medicaid number should also be included. One simple referral form is a three-part Speed Letter that can be found in any stationery or business supply store. States may have a specific referral form, separate or part of their reimbursement form, to be used by them for information and reporting purposes.
3. A decision should be made whether the parent is capable of managing the referral alone. Many parents are not. Some will be capable of getting the child to the right place on time. Others may be capable but may be unable to get the child to the appointment because of illness, other demands on their time and energies, or lack of transportation. The social worker or health aide can assume responsibility for helping patients get to their appointments. Medical students, community organizations, or volunteers can also be used to help patients keep their appointments. Under the EPSDT program, transportation assistance, when necessary, is to be provided.
4. One copy of the referral letter should be retained by the person responsible for the child's record; this copy should be the basis for ensuring that the referral was accomplished.
5. One copy of the letter should go with the child and the person assisting him to the source of referral. If the family is not fluent in the language commonly spoken in the area, the person who is accom-

panying the patient must be able to translate. The presence of a translator at the referral source should not be taken for granted.

6. Completed referrals must be assured. Referral sources make appointments they expect will be kept. If appointments are not kept, the referral source may become reluctant to accept future referrals.
7. The provider of the treatment or referral care should assume responsibility for the child's care within the area of his discipline. Sometimes it is necessary for the worker to make only one visit with the child and parents, then withdraw. Sometimes continuing attention is required.
8. The provider receiving a referral must answer it. The person who has made the referral will not know the outcome until there is a reply. This is more than a courtesy; it is basic to the information system between providers and for EPSDT program management.
9. To manage the referral, a control form which has the following elements can be developed:

   —name of the child
   —name, address, and telephone number of the parent or guardian
   —the problems found
   —the party responsible for the follow-up and referral
   —when the referral was accomplished
   —how the condition or disease was tended to
   —recommendations for follow-up care, if any

This is an especially valuable form if the patient's medical record does not stay with the source initiating the referral.

Records, Charts, and Forms

A substantial amount of record keeping is necessary in an EPSDT program. Basic records are needed whether the program is based on screening and referrals or on comprehensive care. These should include, but are not limited to, the following:

1. Appointment Card. Appointment cards which can be given to the patient or, less effectively, mailed as a post card are useful. These cards should be in the language spoken by the patients. The card should be simply worded so it can be easily read and understood.
2. Appointment Book. Many calendars or journals, which can be obtained from any stationery store, can be used as appointment books. Also, some companies specialize in record-keeping books. A

code to indicate the outcome of appointments is useful (e.g., K = kept appointment, NS = no show, C = cancellation, RA = reappointment made, WI = walk-in). An analysis of the ratio of appointments kept to appointments made is the key to evaluating the effectiveness of the record and appointment systems.

3. Consent Form. Most health facilities require legal consent forms which give the parents' or guardian's permission for examination and/or treatment of the child. Children frequently come in without their parents; therefore, obtaining a signed consent form is mandatory. When the signed consent form is not available, the care giver is faced with the legal jeopardy of treating the child. If possible, the parent should be present when the child is seen. If this is not possible, it is necessary to have a consent form which gives the broadest consent legally possible signed ahead of time.

4. Claim Form. The claim form shows the information necessary to identify the patient, provides necessary statistical information, and serves as the basis for billing. An intelligent and competent person should sit at the front desk to handle appointments and make out forms.

5. Patient Record. Most medical records contain information about the child's birth and developmental history, past medical history, immunization data, and family history. Specifically, the basic components are:

   —a history form showing such items as immunizations and illnesses
   —a problem list
   —a flow chart showing laboratory and screening tests
   —growth and development charts

   The information should be organized into a legible and concise format so the health professional can use the data and the narrative to identify problems. (See Chapter 6 and reference to the "problem oriented record")

   The three main dangers to avoid in entering information in records are:

   —obtaining too much information
   —obtaining too little information
   —not organizing the record so it is useful to others

   Many physicians, especially younger ones, write so much information that it loses its meaning. Other physicians, especially those in private practice who know their patients well, are accustomed to writing a minimum amount of information in their records, and

much of this is code. The physician participating in screening clinics, neighborhood health centers, or other types of group practice may have to make an adjustment in the quantity of information recorded in relation to the information needed.

When a child's medical history is transmitted from one health provider to another, the two basic types of information needed are the problem list and the routine health maintenance data. There is a need for the development of record systems which are amenable to computerization but simple enough to be used without a computer.

6. Reimbursement Form. The health care provider will probably have to use the billing form required by the third party payer. The payer, the State Medicaid Agency, has an obligation to make billing as easy as possible for providers, and the providers should organize their operations to make billing simple and efficient. If the claim form is properly constructed and the person recording information in it is competent, relatively untrained clerks may be used for billing. A well designed billing form may also be used for encounter and statistical purposes.

   Several States have developed a one-page form combining screening, immunization, and reimbursement information.[5]

7. Immunization Record. Parents seldom remember all of a child's immunizations. The parent should be given a card indicating the child's immunization history. If the patient moves, this card will provide information to a new provider.[6]

Terminology

The use of uniform terminology will aid in making record-keeping and case management as efficient as possible. Two publications are recommended:

1. *Procedural Terminology for Pediatricians*, American Academy of Pediatrics, P.O. Box 1034, Evanston, Illinois 60204
2. *International Classification of Disease, U.S. Public Health Service*, Government Printing Office, Washington, D.C. 20402

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[5]Not necessarily recommended, but typical of current efforts are the forms developed by South Carolina and Missouri. Copies may be obtained by writing the State Medicaid Agency.

[6]Durable, wallet size Immunization Record Cards may be obtained from the American Academy of Pediatrics, P.O. Box 1034, Evanston, Illinois 60204. 50¢ each, lots of 1000, $75.

Manuals

Manuals are an important tool for organizing programs and resources. They should be developed at every level of administration to help implement the EPSDT mandate.

The manuals should be written to satisfy the needs of the provider as well as the agency administering the program. This means that, in addition to suggestions on how to requisition and fill out forms, the manual should include a complete guide to resources, including instructions on how to make the best use of each resource.

Medical Advisory Committees

Critical to the effective organization of resources for delivery of EPSDT services is input from professional provider organizations. This is equally true at State, county, and city levels. In addition to the local medical societies and primary care physician groups, such as the State chapters of the American Academy of Pediatrics and the American Academy of Family Physicians, State and local organizations representing osteopaths, internists, dentists, nurses, to name but a few, should be identified, contacted, and invited to serve. In view of the growing changing nature of the EPSDT program, medical advisory activities should be organized for ongoing involvement in the program, as well as to participate in the planning, development, and early implementation stages.

CHAPTER 4

COST AND EVALUATION OF A PROGRAM

Planning and Budgeting the Program

The complicated inter-relationships of funding, service resources commitment, governmental organization, and State geography suggest that each State, county, or local agency needs to work out its own budget based on certain fundamental principles. This chapter will attempt to point out some of these principles.

The most significant points that can be made with regard to program and budget are the following:

1. Program and budget cannot be dealt with separately; they are inseparable. The administrator and the physician must develop program and budget together. It is unwise for EPSDT to proceed directly from the Federal regulations to the State administrator for implementation without physician involvement.
2. Management - as is true of medicine - is an art as well as a science. The "educated guess" and the "calculated risk" are significant tools. In management, the best possible decision has to be made continually or the best possible working hypothesis has to be adapted.

Budget Development

The following questions need answers before developing the budget for an EPSDT program:

— How many children will be in the program
— What are the time frames of the budget period
— Will services be purchased or provided
— What will the program cost per child
— What will the program cost in total
— What available resources can be applied to the program, whether in money or services

— How much federal money is available for reimbursement
— What additional resources can be obtained
— Are the available financial resources sufficient to fund the program
— Are the available service resources sufficient for the program
— How can the program be modified to meet resource limitations and preserve program integrity.

Calculating the Cost of Services

After the program has been defined, the number of children to be covered by it will have to be estimated and their ages, geographical distribution, health status, and needs noted.

The breakdown of children by age multiplied by the number of visits by ages specified in the State's well child care protocol will give some indication of the number of well child visits needed. This figure will have to be modified later to compensate for the impossibility of all children making all the visits given in the protocol.

Estimates need to be made of the number of sick child visits that will be necessary and how they will interrelate with the well child visits. Considerable well child care is delivered when the sick child is seen; therefore, well child and sick child visits cannot be completely dissassociated when costing a program.

Some estimate needs to be made of the cost of referral services to be developed. There will be more referrals from a screening site than from a comprehensive care program.

Statistics are available which attempt to define the "yield" to be derived from screenings. However, these data do not necessarily apply to any given population. For instance, general statistics for ova and parasite screening yields would not be relevant to a Medicaid population of new migrants from Puerto Rico. And, undue general statistics on screening yields for lead absorption would not apply to a population living in tenement houses painted with lead paint.

The initial surge of services to correct chronic situations in a new program delivering care to a previously neglected population will far exceed the need for maintenance services after the untreated conditions have been cared for. Each State must make its own best estimates on costs of referral and treatment services based on knowledge of the character of the Medicaid population, the problems that population is likely to have, and the degree to which those problems have been cared for in the past. Maternal and Child Health and State Health Departments usually have epidemiological data for various sections of the state.

Dental costs should be developed separately, rather than appended to, or lost in the medical program. The cost of dental care has a different set of factors that affect it. A program which ignores dental care is not a comprehensive health care program.

Some gross estimates of the cost per child per service and the total cost of services can be made. For example, if there is a commitment to comprehensive health care for each child which includes an average of two well child visits per year, full hospitalization as needed, and a small to moderate initial surge of services needed to correct chronic problems, an estimate of cost might be made on the basis of purchase of services as follows:

1. a) Five ambulatory visits covering sich care, well care, and referral services at an average of $18 per visit equals $90.
   b) Three dental visits at an average of $15 per visit equals $45.

   These costs total $135 per year per child for ambulatory services. Indirect and organizational cost services provided separately - such as outreach, managing the referral, other health support services, and monitoring - will be added later.

2. The proposed EPSDT plan should be looked at to determine if the resources required to provide care are available. If five or six ambulatory visits per child are estimated and these visits are multiplied by the number of children in an area or in a State, there may be so many visits that the number of available physicians could not possibly handle them. If so, a decision will have to be made about reducing the level of comprehensiveness of care, increasing the delivery of services by the State or county, or developing programs to expand the capability of physicians through the use of ancillary personnel. Separate programs may have to be planned for areas which differ drastically in such factors as population density, access to resources, types of health problems, and income level of population.

3. After the care-giving program has been defined in relation to the goals and resources available, indirect costs such as outreach, referral management and other health support services, organization at State and local levels, monitoring, and other administrative costs should be considered.

4. After all costs are determined, the test of reason must be applied. Good sense and experience should never be ignored in evaluating the cost of a program. How these costs relate to present expenditures and to the cost of providing care through existing health resources, the cost benefit resulting from preventive and comprehen-

sive care versus fragmented crisis care, and extensive use of costly emergency room facilities, should be determined.

5. The total cost of the program should be readjusted based on (a) the number of children who can be reached, (b) the available services and resources, and (c) the resources that can be reassigned or developed. If there are 500,000 AFDC children in a State, some of them may not receive care in the first year or second year. Moreover, if a State has had a commitment to health care for AFDC children, there will be a budgeted expenditure which can be applied to the new program. Other resources might also be reassignment to this program, such as the use of social workers and paraprofessional health aides for outreach and case management. The State can determine the new resources and monies needed by defining its total program and subtracting the available resources and those that can be reassigned. In some instances, health aides may be recruited from the welfare rolls with resulting savings in welfare costs.

   The budgeting process should show reasonable estimates of cost per child and per program, and the administrator must be prepared to defend those costs. The advice and support of physicians and physician organizations, and the development of professional advisory committees can be extremely helpful to the administrator.

Cost Efficiency

Three basic criteria should be used to measure the cost efficiency of a comprehensive center provider:

- The relation of the salary of the care provider to the total cost of a visit
- The relationship of actual utilization of services to potential utilization
- The volume of visits and service revenue representing a breakeven point for the provider.

To expand on these criteria:

If an average visit to a health care provider is 15 minutes with a nurse paid $6 an hour, the provider cost per visit is $1.50. If the provider is a physician paid $20 per hour, the provider cost is $5 for a 15-minute visit. If the total cost per visit is more than three times the cost of the provider time, the visit is probably not cost effective.

A common sense evaluation should be made of whether facilities are being used efficiently. In some programs a physician might see patients at the rate of one per hour. This is inefficient utilization of physician time and results in a high cost per visit. Most pediatricians can estimate the number of patients that can be seen without sacrificing quality. The total depends on the relative numbers of new, sick, and well patients.

If a health facility costs $300 per day to run, and the reimbursement per visit is $15, the financial breakeven point based on earned money is 20 visits per day. This financial breakeven point is important. The number of patients who must be seen for the financial survival of the health facility is known. If the breakeven number of visits is high, reasons for the high costs can be sought. Low fees can have the same effect as high costs. There are screening clinics costing $50 per visit because of underutilization, while private pediatricians may provide comprehensive visits at a third or less of that cost.

Cost of Outreach, Case Management, and Other Health Support Services

The cost and cost effectiveness of outreach techniques vary considerably. Distributing information through communication media or by mailings is not expensive, but it also is not effective in reaching the children whose families are most alienated and probably most in need of care. Reaching out on a one-to-one basis whereby outreach workers inform and assist individual children in attaining care seems to be the most effective method, but is also more costly. Appropriate balance between these extremes, based on local needs and available resources, should be sought. Seventy-five percent federal reimbursement is available for local staff providing health support services under direct professional medical supervision.

Cost of Referral

The cost of referral depends on the amount and cost of transportation required, the need for patients to be accompanied by interpreters or outreach workers, the yields of referrals (which will depend on the nature of the population), and the level of sophistication of the screening program. Most programs can expect an initial surge of referrals because of unmet chronic conditions. Referral costs will decrease when this initial surge is over.

Referral costs can be particularly expensive when personnel are needed to accompany patients and if the referral visit takes a long time.

As with outreach, referral represents an excellent opportunity to employ welfare clients as health aides to accompany patients and parents.

Indirect Cost at the Level of Policy Making and Basic Development

There will be costs for such functions as:

- — developing and implementing policy
- — paying bills
- — generating information to be used as the basis for outreach and case management
- — developing information to be used as the basis for reporting to the Federal Government
- — performing utilization review and quality control
- — staff training

Reimbursement

If a State contracts with providers to serve Medicaid patients, reimbursement levels should be at usual, customary, and prevailing levels. The Medicaid Act requires that reimbursement levels make available services to recipients as adequate as those to the general population. Both recipients and provider group representatives on an advisory council can point out where inadequate payments threaten the availability of services.

Payment for services should be made in a reasonable time. Most physicians expect that payment for services will be made within 60 days after submittal of a bill. When a State delays payment beyond that of other third party payers, it risks loss of good will of providers and the availability of their services.

Equivalency

EPSDT is not intended to duplicate services or cause children already receiving adequate care to be removed from their usual source of care. Regulations are being developed so States may receive "credit" toward

fulfilling the EPSDT mandate through equivalent services rendered to children by health care providers. This will enable States to identify providers not currently participating in EPSDT programs and to bring them into the State's system.

Evaluation

To evaluate its program, a State needs to:

- — define acceptable goals
- — demonstrate an honest commitment of resources to these goals
- — develop a plan for delivering EPSDT that is realistic, philosophically sound, and consistent with its goals and resources

When a State's plan has been approved, the State must be accountable for its implementation. A State which defines its goals as the delivery of comprehensive and continuing care to all eligibles should be able to demonstrate that

- — reasonable efforts are being made to get children into care
- — there are adequate resources to deliver the necessary care
- — it pays its providers at competitive levels
- — its Medicaid budget is realistic to cover all necessary medical and administrative costs

The kinds of information required under an evaluation system should be based upon use of adequate codes for treatment vs costs in a good billing system. A model EPSDT Management Information System is being developed by the Federal EPSDT agency for initial tryout in one State (Georgia). It treats the evaluation of operational activities and program management, and allows the States the choice of computerization.

Audit

Providers need to be held accountable for delivery of care that is at an acceptable level of quality and quantity. This can be done in the following way:

1. There should be a written understanding between the EPSDT agency and the provider detailing the agreements by each party in providing care. The EPSDT agency should state clearly what it wants, and the provider should understand what is expected of him.

2. A requirement that the provider keep reasonably detailed records should be included in the agreement.

3. Samples of patient records should be routinely audited to ensure that children are receiving proper care. This audit should be done inoffensively and conveniently for the provider, and it should be done in cooperation with professional societies. There must be an opportunity for the provider to comment on the audit and for these comments to be part of the report.

The on-site audit has been the basic evaluation tool in health care delivery. It is against the audit that all other things are calibrated.

PART TWO: DIAGNOSIS TREATMENT, AND FOLLOW-UP

CHAPTER 5

HEALTH SUPERVISION, PREVENTIVE SERVICES, AND PERIODICITY

Attempts to establish protocols for routine health supervision have met with variable success. A model protocol for health supervision of children and youth entitled "Recommendations for Preventive Care of Children and Youth" has been developed by the American Academy of Pediatrics Committee on Standards of Child Health Care. Relevant excerpts from this document are indicated at the end of this chapter.[7] However, each State or community should set its own standards for what is usual, customary, and appropriate for the needs of its children. Protocols should be developed in cooperation with appropriate professional organizations in the State.

The primary purpose of a health supervision visit is to assess the child's functioning in the context of the family, school, and community environment. The visit should be regarded as a method of ensuring continuity of evaluation of the well child as compared to a visit for illness wherein most of the attention is directed toward solving the illness problems.

Screening should not include procedures of little or no value in specific communities. For example, tests for sickle cell traits are unnecessary in a community with no black children. Routine tuberculin testing should be limited if there is a negligible prevalence of tuberculosis in the community. Examinations for ova and parasites should be part of the protocol only in areas of endemic parasite infection.

Routine health care also can be delivered to children when they are being seen for illness. Combining well and sick care may require considerable flexibility from the health care provider; but upper respiratory infections, for example, may be one of the best outreach mechanisms for health supervision.

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[7]See also "A Guide to Screening - EPSDT - Medicaid," SRS/HEW in cooperation with the American Academy of Pediatrics, P.O. Box 1034, Evanston, Illinois, 60204, 1974.

RECOMMENDATIONS FOR PREVENTIVE HEALTH CARE OF CHILDREN AND YOUTH

Committee on Standards of Child Health Care
(First published, June 1974)

The Recommendations for Preventive Health Care for Children and Youth presented below reflect the changes occurring in pediatric practice at the present time. Increased emphasis on meeting the individual needs of each child rather than trying to fit everyone into a mold is the primary thrust. Personal counseling of the older child is another emphasis. Reduction in tuberculin testing reflects the diminishing incidence of this disease. Urinary cultures in all females rather than repeated urinalyses is made feasible by easy, inexpensive methods. Future editions may well introduce new procedures such as cholesterol determinations in the very young.

The schedule has been subjected to rigorous critique by the entire membership through mail survey and discussion at each district meeting as well as by experts in various fields. It is hoped that the schedule may be a tool through whose use more and more children may receive needed care.

The Committee on Standards is concerned with the health supervision *all* children should receive. Recent published studies have demonstrated that some health supervision procedures need not be repeated with the frequency previously recommended and traditionally accepted.

The optimal number of visits or preventive procedures for all children or their parents is at present impossible to establish. Therefore, the "Recommendations for Preventive Health Care of Children and Youth" represents a guide for the care of well children who receive competent parenting, who have not manifested any important health problems, and who are growing and developing satisfactorily.

Circumstances which may indicate the need for additional visits or procedures include:

1. First born or adopted children, or those not with natural parents
2. Parents with a particular need for education and guidance
3. Disadvantaged social or economic environment
4. The presence or possibility of perinatal disorders (such as low birth weight), congenital defects or familial disease
5. Acquired illness or previously identified disease or problems

The services which may be required for an individual child or groups of children must be determined by health care providers. The recommendations are not meant to interfere with long term parent-child-physician relationships which have proved so valuable in preventive health care. The schedule may well vary at different periods of life, at times of crisis, and with changing family conditions. Physicians, third party payers and the public must appreciate that the accompanying recommended schedule constitutes a guideline of care for children and youth, and that the needs of the individual child will be met only by providing additional services as they become necessary.

The Committee on Standards emphasizes that at least the following should be completed at every health supervision visit: initial or interval history, measurements (properly recorded), sensory screening as indicated, developmental appraisal, physical examination or assessment as determined by the responsible physician,[8] immunizations and diagnostic tests as indicated, discussion of findings and counseling. The repetition of some items is advised because of the "risk factors" present in the three components of any practice - the children, their caretakers (e.g., families, schools) and the health care providers. If a copy of the schedule is used as a "jog sheet" in each child's chart, the accomplishment of the items could be inserted in the square.

The value of routine urinalysis and/or urine culture for well children is controversial. The new recommendations may well be altered in the future. Recent studies have validated the definite yield of positive cultures in apparently well females, and simple and inexpensive screening culture methods make this procedure practical for office use. Therefore, the Committee believes cultures should be done as suggested in the revised schedule. The Committee also emphasizes that both urinalyses and urine cultures should be freely employed in children of both sexes who are ill or failing to thrive.

Discussion and counseling is a most important element of child health care, both in establishing long range relationships between family and physician and in answering immediate problems.

The provider is responsible for assuring that the benefits which might be gained from the omission of procedures are compensated for in some other way, such as previous instruction of demonstrably competent parents, or good community or school screening programs.

The number of visits suggested in these recommendations has been reduced because of the decrease in feeding problems and in certain illness-

[8]Observation of the completely undressed child to include mouth, upper respiratory tract, skin, musculature, motor activity and behavior.

es during the past few decades. The intervals are made flexible to avoid a rigid attitude toward the tradition of specific ages (e.g., one year); also many physicians incorporate, when feasible, a health supervision visit with a visit for a minor problem. Education of camp and school directors may be necessary to gain their acceptance of the diminished need for frequent examinations after age 5 years. Procedures which, in the opinion of the Committee and consultants no longer make a significant contribution to health outcomes, have been eliminated.

During this period of rapid change, the Committee feels that it should not specify the principal health care provider for each health supervision visit; the physician or facility should make this decision based on the availability of personnel. Custom, necessity and the preferences of both health care recipients and providers will also influence this decision. Where certain visits are accomplished by non-physicians, as in well baby clinics, a physician should always be available to check questionable or serious findings, although this need not be on the same day. Presumably, most physicians will wish to have the assistant accomplish part of the history, the measurements and the screening tests before they see the patient, and perform procedures indicated by the suggested schedule after the physician's examination.

The recommendations reflect experiences of the practicing pediatric community. The opinions of 250 physicians recently consulted about health supervision by the Joint Committee on Quality Assurance by Ambulatory Child Health Care[9] have also been extremely valuable.

The Committee reaffirms that preventive pediatrics is the core of quality medical care for children. It is the sound basis on which the opportunities of each child for optimal physical, intellectual, and emotional growth and development are built.

[9]Composed of representatives appointed by the American Academy of Pediatrics; American Academy of Family Physicians; American Medical Association; American Public Health Association; Ambulatory Pediatric Association; American Osteopathic Association; the Department of Health, Education, and Welfare; and the National Medical Association.

RECOMMENDATIONS FOR PREVENTIVE HEALTH CARE[1]

The "Recommendations for Preventive Health Care of Children and Youth" represents a guide for the care of well children who receive competent parenting, who have not manifested any important health problems and who are growing and developing satisfactorily. Circumstances which may indicate the need for additional visits are outlined in the accompanying text.

AGE[2]	2-4 Wks.	2-3 Mos.	4-5 Mos.	6-7 Mos.	9-10 Mos.	12-15 Mos.	16-19 Mos.	23-25 Mos.	35-37 Mos.	5-6 Yrs.	8-9 Yrs.	11-12 Yrs.	13-15 Yrs.	16-21 Yrs.
HISTORY														
Initial	At first visit													
Interval	At each visit													
MEASUREMENTS														
Height & Weight	At each visit													
Head Circumference	▨	▨		▨		▨		▨						
Blood Pressure									▨	▨	▨	▨	▨	▨
SENSORY SCREENING														
Sight[3]	▨	▨		▨					▨ OR	▨	▨	▨	▨	
Hearing[4]				▨					▨ OR	▨				
DEVELOPMENTAL APPRAISAL[5]	At each visit													
PHYSICAL EXAM	At each visit													
PROCEDURES[6]														
Immunization		▨	▨	▨		▨	▨			▨			▨	
Tuberculin Test[7]					▨				▨			▨		
Hematocrit or Hgb.					▨				▨ OR	▨		▨		
Urinalysis[8]								▨					▨	
Urine Culture (girls only)[9]									▨	▨	▨			
DISCUSSION & COUNSELING[10]	At each visit													
DENTAL SCREENING[11]	At each visit													
INIT. DENTIST'S EXAM[12]									▨					

1. Applicable in content of accompanying explanatory text and footnote references.
2. If a child comes under care for the first time at any point on the Schedule, or if any items are not accomplished at the suggested age, the Schedule should be brought up-to-date at the earliest possible time.
3. *Manual on Standards of Child Health Care*, 2nd Edition. Page 8 for details.
4. Ibid. Page 9, 127-130.
5. Ibid. Page 23-32, 120-126, 132-134, 140-144. Developmental appraisal is an integral part of each visit. Employ a standardized format at any time there is suspicion of developmental delay.
6. Ibid, page 131. *Report of the Committee on Infectious Diseases*, (Red Book) 17th Edition, 1973.
7. May be indicated yearly in certain areas and population.
8. At least 5-test dipstick
9. Taken in morning, see Kunin, C.M., *Detection, Prevention and Management of Urinary Tract Infection*, Lea & Febiger, Philadelphia, 1972, Pages 60-69, for suggested methods.
10. *Manual on Standards of Child Health Care*, 2nd Edition, Pages 13-21. Discussion and counseling of child by the physician is of increasing importance at age 11 years and thereafter.
11. Ibid., Pages 11-13. Appendix 1, !. 135. Physician should inspect teeth and check on dental hygiene throughout childhood.
12. Subsequent exams as prescribed by dentist.

Key: to be performed.

CHAPTER 6

PROBLEM MANAGEMENT

This chapter is concerned with aspects of diagnosis and problem management of conditions detected through screening or health evaluation. It is arranged and presented as a companion piece to Part Two of "A Guide to Screening, EPSDT-Medicaid."[10] Specific cross references are set forth with each of the sections of this chapter.

The term problem management is used to suggest steps that may be taken to resolve a medical problem that has been detected. Problem management includes social, administrative, and organizational components as well as diagnosis and treatment of the medical condition. "A Guide to Screening" is designed to give detailed information on screening tests, their purpose and rationale, whom and when to screen, methods of screening, and follow-up on positive results. In the following sections certain aspects of problem management of conditions detected by screening will be considered. More specific details of diagnosis and treatment are best obtained from standard pediatric textbooks.

History and Physical Examination

The purpose of the history and physical examination in a screening program is to detect health problems that may require further diagnosis and/or treatment. In comprehensive care, the same purpose is served, and in addition, the physician has an opportunity to establish a relationship with a child and family.

Chapter 10 of "A Guide to Screening" may be used to assist the allied health professional in performing an initial evaluation. The child with an abnormal finding should be seen by a physician who will confirm the results and perform further studies to define the problem, establish a diagnosis, prescribe necessary treatment, and refer the child for further evaluation if necessary. The decision on "when to refer" may be difficult if a phy-

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[10]op.cit., "A Guide to Screening, EPSDT-Medicaid," Part Two, Screening Procedures.

sician is not present at the screening examination. When a physician is present, diagnosis and treatment may be given without further referral. If screening is performed by allied health personnel in the absence of a physician, written guidelines for referrals should have been established by the physician responsible for the medical supervision. Standing orders for treatment of minor problems and administration of immunizations are also required.

The following examples are illustrative:

1. A screening examination conducted by a nurse detects a 2-year-old child with severe knock knees and toeing in. The examination is conducted in a rural area with a physician available for telephone consultation. The nurse informs the physician of the findings, and the determination is made to refer the child for an orthopedic consultation at the community hospital 20 miles away. The nurse and aide inform the parents of the problem, explain the need for the consultation, make arrangements for an appointment and transportation, and write a referral letter. The health aide contacts the family to confirm the arrangements for transportation. After the consultation she receives the recommendation from the orthopedist that special shoes are required. The aide then assists the family in filling the prescription for orthopedic shoes and arranges for a follow-up appointment in 6 months. The supervising physician is informed of the outcome.

2. A health aide detects head lice in a 4-year-old child. The aide refers to standing orders on head lice which give directions for the use of recommended shampoo, combing, and counseling for the family. The health aide performs the recommendations under supervision of the public health nurse and arranges for a follow-up home visit in 2 weeks. The physician involvement was limited to developing the standing orders and giving permission for the shampoo to be dispensed.

3. A public health nurse discovers a 2-year-old child with multiple problems of chronic diarrhea, poor weight gain, delayed motor development, and a possible ear infection.

   The nurse arranges for the physician to see the child immediately and begin a diagnostic work-up for the long-standing problems, to confirm the diagnosis of an ear infection, and to prescribe appropriate therapy. The child is followed closely in the physician's office.

Immunizations[11]

There should be standing orders for administration of immunizations in the screening program. Any child who needs immunizations should be given them during the screening examination. The standing orders should cover exceptions or unusual circumstances.

In most States and communities the epidemiology units of the Public Health Department will provide vaccines and equipment for their administration. They should be contacted and communications established regarding reporting procedures, information exchange, etc. New information and recommendations regarding immunizations may be obtained from the weekly Morbidity and Mortality Report of the U.S. Public Health Service.

A comprehensive coverage of immunizations - including recommended schedules, immunizing agents, techniques of administration, precautions, and contraindications - is given in the American Academy of Pediatrics "Report of the Committee on Infectious Disease" (Red Book), 18th edition, 1974, which may be obtained for $3.00 from the American Academy of Pediatrics, P.O. Box 1034, Evanston, Illinois, 60204. A personal wallet-size Immunization Record Card may also be obtained from the Academy at the same address for 50¢; 10 or more, 15¢ each.

Dental Care[12,13]

All children need dental care. Screening for dental disease is not nearly as important as enrolling children in a dental program for prevention of disease, education, diagnosis, and treatment. Each health examination of a child should include inspection of the mouth, teeth and gums. Children with obvious dental disease should be referred for preventive dental care between the ages of 3 to 5 years. Ideally, this care should be provided every 6 months. The non-dental health professional can help in the following ways:

- — detecting dental disease and referring for care
- — reinforcing the need for regular dental care
- — recommending and reinforcing dental hygiene, tooth brushing, and use of fluoride toothpaste

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[11]See "A Guide to Screening", Chapter 11.

[12]ibid., "A Guide to Screening," Chapter 12

[13]See also "A Guide to Dental Care - EPSDT-Medicaid." SRS/HEW in cooperation with the American Society of Dentistry for Children and the American Academy of Pedodontics, 1975.

— providing tablets or topical fluoride when the water is not fluoridated
— assisting in community efforts to fluoridate water supplies if this is not in effect
— counseling against eating candy and high sugar content foods, and the giving of lollipops to children
— counseling against use of a night-feeding bottle with sweetened contents or milk
— becoming knowledgeable about dental resources, including private dentists, school programs, and dental education facilities in the community

Vision[14]

Data from the National Health Survey, February 1972, indicated that 7% of 6-year-old children had a visual acuity for binocular distance vision of 20/40, and that this figure rose to 11% at age 11 years. At 6 years of age, 1% of children had visual acuity of 20/100; and this figure rose to 8% at 11 years. Five percent of preschool children have one or more visual defects. Most of these children are nearsighted (87%); the rest are farsighted or have squint.[15]

Diagnosis:

Children aged 3 to 6 years who demonstrate a visual acuity of less than 20/40 in either eye, or who demonstrate a one-line difference in visual acuity between the two eyes within the passing range, should have further evaluation. Children who demonstrate squint by the cover-uncover test or by parental history should be referred. Further evaluation should also be considered for children who show evidence of infection, enlarged or hazy cornea, excessive blinking, cross eyes, amblyopia or other eye abnormalities.

Interpretation of Results of Screening Examinations:

There is usually little difficulty in determining that visual acuity is diminished in an older child. Vision screening is more difficult to perform in a

[14]op. cit., "A Guide to Screening," Chapter 13.

[15]Schwarting, B.H.: Testing Infants' Vision. American Journal of Optholomology, 38:174 1954.

preschool child, and a screener may be even less confident in the validity of a determination of muscle imbalance or other pathology.

Referral:

It is best to refer a child for a more complete eye examination when any doubt exists, or when, despite normal testing, the parents report that the child's eyes turn in or out. The standards for referral and expertise of screeners should be developed by ophthalmologists or optometrists who have had experience treating children. A child who fails the initial screening test and is confirmed to have abnormal vision on retesting should be referred to the family physician or a specialist for further evaluation. Whether the referral is to an optometrist, an ophthalmologist, or ophthalmology service of a hospital depends on prevailing community practice, resources, and the advice of the local or State EPSDT committee. Most specialists will perform an examination which includes dilating the pupil and full refraction, muscle testing, depth perception, stereopsis, color vision testing, and fundoscopy.

Counseling and Follow-up;

The specialist should inform the child and parents of the extent or absence of eye disease, and should recommend necessary procedures such as prescription of glasses or special treatment for lazy eye blindness (amblyopia). These results and recommendations should be given to the referring physican and/or screener. The specialist may need to see the child at regular intervals, or may request a follow-up in 1 or 2 years. These follow-up visits will need to be acted on by the referring physician or by EPSDT program staff to see that they are made.

Resources:

Many communities have opthalmologists and optometrists in private or hospital practice who will accept referrals and may also help to establish and maintain the quality of screening activities by their involvement with EPSDT. In some communities, assistance may be obtained through State and local departments of public health and school health vision services, the Lion's Club, or State societies for ophthalmology or optometry. Visually handicapped children may be helped by the National Association for the Visually Handicapped or the U.S. Department of Health, Education and Welfare's Bureau of Education for the Handicapped in the Department of Special Education in each State. Because the availability and comprehensiveness of supportive services differ in each State, assistance in formulat-

ing resource lists may be obtained through local eye specialists who are familiar with these resources.

Hearing[16]

Approximately one child per 1,000 has severe hearing loss requiring a hearing aid or special education. Eight children per 1,000 have persistent impairment in both ears of more than 30 decibels and approximately 15 to 30 children per 1,000 have some degree of hearing impairment.

Diagnosis:

A child with a detected hearing loss of 15 to 25 decibels at any two frequencies should be retested, and if confirmed, referred for evaluation by a physician. An infant who fails to respond appropriately for age to speech or other sounds should also be referred for evaluation. The physician should take into consideration any family history of deafness; a history of prenatal infection in the mother, such as rubella, low birth weight, neonatal infections and jaundice, a history of ear infections in infancy, and anatomic abnormalities of the ear, nose and throat. The physician will make an initial determination whether the hearing loss might be caused by wax in the ear canals or fluid, or infection in the middle ear. When these conditions have been adequately treated and a persistent, significant hearing loss remains, the child should be referred for further evaluation. The physician should also note and deal appropriately with speech problems in the child with hearing loss.

Referral:

The child may initially be referred to an audiologist who will confirm the presence or absence of hearing by more sophisticated testing than used in a screening program. An evaluation may also be performed by an otolaryngologist - a physician specializing in diseases of the ear, nose and throat. The results of these evaluations will determine recommendations for treatment, such as surgery or hearing aids and referrals for speech therapy. A child with a severe hearing loss may need special education and rehabilitation for many years.

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[16]See "A Guide to Screeing," Chapter 14.

Counseling and Follow-up:

The otolaryngologist and audiologist should explain the nature and extent of the hearing problem and should provide information on the treatment needed and probable outcome. These recommendations should include referrals for special education when needed and follow-up. They should identify community resources which should be involved in helping the child with a hearing problem

Resources:

Most States have information for parents, educators and health professionals listing resources for children with impaired hearing. The State Departments of Special Education and Public Health should be contacted for information about educational facilities and assistance with hearing aids. The State Council on Disabilities as well as the Vocational Rehabilitation Agency are also resources.

A number of state evaluation centers in hospitals and clinics offer audiologic examinations and, in some instances, therapy. The centers may be registered with the American Board of Examiners of Speech Pathology. State and national organizations which serve the special needs of deaf and audiologically impaired children are:

American Speech and Hearing Association
9030 Old Georgetown Road
Washington, D.C. 20014

Alexander Graham Bell Association
The Volta Bureau
3417 Volta Place, N.W.
Washington, D.C. 20007

Convention of American Instruction of the Deaf
Parent Section
5043 Wisconsin Avenue, N.W.
Washington, D.C. 20016

National Association for the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

Easter Seal Societies in most States.

Growth and Nutrition[17]

Reliable current data on prevalence of growth problems in children are not available. Information from children and youth projects in 1968 revealed weight and growth problems in children less than 6 years old in approximately 11 to 15 per 1,000 in normal birth weight children. Prevalence of overweight children was reported as between 5 and 7 per 1,000. The author's experience with an inner-city, indigent population has revealed an approximate figure of 2% of children with severe failure to thrive caused by malnutrition and another 10% with moderate growth impairment. Approximately 5% of this population were overweight.

Diagnosis:

Measurement of height and weight should be plotted graphically on growth charts[18] to determine the percentile rating. The rate of growth may be assessed by comparing current measurements with previous ones. Further evaluation of the child is indicated if a measurement is above the ninety-seventy percentile or below the third percentile, or the rate of growth has changed more than 20 percentile points. Children in reasonably good health tend to grow along their own percentile curve on a growth chart. A child who gains weight but not height over a period of one year is unlikely to have organic disease, whereas a child who stops gaining or actually loses weight is more likely to have a problem requiring evaluation. In most circumstances, both failure to grow and obesity indicate nutrition problems. In only a relatively small portion of children is growth retardation caused by organic disease such as chronic respiratory, cardiac, renal, gastrointestinal, or endocrinologic.

Evaluation by a physician is suggested for the following groups:

- — children who are below the third percentile for height and weight
- — children who demonstrate weight loss or no weight gain over a period of time
- — children who are considerably overweight in proportion to their height

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[17] op. cit., "A Guide to Screening," Chapter 15.

[18] Iowa growth charts are available from Order Department, Sidwell Building, University of Iowa, Iowa City, Iowa. Harvard growth charts may be obtained from Mead Johnson Company, Evansville, Indiana 47721, or Ross Laboratories, Columbus, Ohio 43216.

Referral:

Referral to a physician should include as much information as possible on growth measurements since the child was born. Growth information on family members may be a valuable indication of a familial basis for short stature or obesity.

Management:

The physician should perform a comprehensive evaluation with emphasis on a nutritional history. A search should be made for organic illness and endocrine and genetic conditions if appropriate. If serious underlying disease is suspected, the child may be sent to a pediatric referral center for more extensive evaluation. If growth problems are caused by malnutrition, efforts must be made to help the family obtain adequate nutrition by using all available community supportive services.

Counseling:

Families with nutritional problems can be helped in obtaining food through the surplus food or food stamp programs or by direct financial assistance. Counseling on budgeting to maintain optimal nutrition within the financial constraints of a family is important. Counseling also requires insight into cultural attitudes toward nutrition so modifications of traditional diets can be accepted. There are many models for nutritional intervention, ranging from hospital-based nutritionists to community aides and agricultural extension services. Experience in these programs indicates that counseling should include practical advice, continued follow-up and, wherever possible, home visits. Obesity in children may not be regarded as a problem by their families, particularly when family members are overweight. Accelerating weight gain in an infant or child indicates the need for intervention, such as restriction of milk and carbohydrates. The American Academy of Pediatrics' manual *School Health: A Guide for Physicians*, Chapter Six - Adolescence, contains information on the problem of obesity in children. It is available at $3.00 a copy from the Academy's headquarters, P. O. Box 1034, Evanston, Illinois 60204.

Resources:

Communities without nutrition programs may need to develop effective ways of providing services. Links between public assistance programs and public health and Visiting Nurses Associations may be established so a family receiving surplus food may also be helped with advice. Indigenous community nutrition aides can be trained to follow through with families

and reinforce counseling by physicians and nurses. WIC programs sponsored by The Department of Agriculture are available in many communities.

Developmental[19]

Screening for developmental problems or impairment should include mental subnormality, seizure disorders, neuromotor disabilities, learning problems and severe emotional disturbances. Three percent of all children have developmental abnormalities which affect their ability to cope with their environment. Fourteen percent of school-age children have emotional problems severe enough to require treatment. The combined prevalence of children with developmental impairment probably approaches 20%, with increased prevalence in lower income families. Developmental problems may remain undetected in many children until they enter kindergarten or first grade because the problems may not be obvious unless specifically looked for. School may be the first challenge to their abilities.

Diagnosis:

A child with severe developmental handicaps usually can be identified easily. Borderline handicaps may be over- or underdiagnosed by an unsophisticated observer. Diagnosis becomes more difficult if testing is complicated by language or cultural differences, or if an emotional disorder overshadows the developmental aspects of the child's performance. In diagnosis of developmental problems there is no substitute for skilled supervision or consultation. Subsequent interviews with parents and information from teachers will provide important, additional, diagnostic criteria. Because development is a continuous process, retesting is invaluable. Ideally, developmental screening should be carried out whenever a child is seen for health care.

Referral and Management:

Children suspected of having developmental problems should be evaluated by a pediatrician or family practitioner experienced in dealing with children. A careful history should be taken with particular emphasis on:

1. Family history of developmental and birth defects

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[19]See "A Guide to Screening," Chapter 16.

2. Birth history, including complications of pregnancy such as maternal infections, prematurity, low birth weight, difficult delivery, cerebral anoxia, jaundice, or other problems of the newborn period
3. Past medical history, including major illness, infections, head trauma, ingestions, and seizures
4. Evaluation of the family and social environment

A complete physical examination, including a neurologic assessment should be carried out. Laboratory and other confirmatory studies should be performed. This evaluation and information from the screening tests will be used to make the diagnosis and determine the need for further referrals. The physician will determine whether the child should be referred to a neurologist, psychologist, child psychiatrist, learning disability specialist, or other health professional. In some communities the referral will be dictated by the available resources as well as by the child's special needs.

Whenever a child is referred, his history should be made available in as much detail as possible. The referring physician is in the best position to obtain the information because he knows the child and family. Similarly, the results of other screening examinations (such as vision, hearing, and blood lead) should be made available to prevent unnecessary duplication. Depending on the nature of the problem, the child should have neurologic studies, including an electroencephalogram (EEG) if a seizure disorder is suspected; psychological evaluations; and other special evaluations related to visual, perceptual and motor functions to establish a diagnosis.

Treatment and Counseling:

When the extent of the child's handicaps are determined, the family should be informed, and recommendations for treatment given to the family and the referring physician. They may be for specific therapy (such as anticonvulsant or other medication) or for advice dealing with the educational and emotional needs of the child. They might require special tutoring or other developmental therapy techniques; these often involve the special education programs in the schools, including the school social worker, special education teacher, and psychologist.

Follow-up:

The need for follow-up is determined by the nature of the problem and the recommendation of the consultants. Follow-up is essential for children with severe handicaps to assess progress and review the treatment plan. If the child has a source of comprehensive care, that source should provide the follow-up if possible. Children on anticonvulsant medication for seizure disorders require close medical supervision.

The child with a learning disability or mild mental retardation may do well in a regular school situation if individual attention can be given; or, special education classes or private tutoring may be necessary. The decision regarding educational placement should be made primarily by the school personnel. However, there should be continuing collaboration between the school and the professional managing treatment to watch for early signs of failure and resultant frustration and emotional problems, and provision made for dealing with them to the extent resources can be made available. Parents also need help in dealing with developmental problems of their children.

Resources:

Pediatricians, pediatric referral centers, university affiliated diagnostic centers, and mental health centers are generally the best sources of information on diagnosis and treatment facilities in the community. Preschool and school programs may also have guidance and treatment capabilities. Other resources in communities may be social service agencies, church and private family counseling agencies, and day care and Head Start programs. The Department of Public Health in most States has some responsibility for preschool programs and may provide information on available resources.

The Department of Mental Health will have resource lists of diagnostic and guidance facilities in community mental health programs. The State Department of Special Education has the responsibility for school programs for children with developmental disabilities.

Tuberculin Sensitivity[20]

The prevalence of tuberculosis infection in children is so low in many communities that routine tuberculin testing of all children can no longer be recommended. However, two groups of children still deserve routine periodic testing:

- — all children who have had contact with a known case of tuberculosis
- — all children living in neighborhoods or communities in which the prevalence of tuberculin sensitivity in school-age children is known to exceed one percent.

It is noteworthy that the incidence of tuberculosis is approximately six times higher among non-white than among white children.

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[20]ibid., "A Guide to Screening," Chapter 17

Diagnosis:

A Mantoux tuberculin reaction is positive when the area of induration (swelling that can be felt at the site of the skin test) is 10 mm or more. A doubtful reaction is an induration between 5 and 9 mm. A negative reaction is an induration less than 5 mm. A multiple puncture test (Tine, Mono-Vacc, or Heaf) is positive if vesiculation is produced, doubtful if the area of induration is more than 2 mm without vesiculation, and negative if the area of induration is less than 2 mm. A positive, multiple puncture test should be confirmed by a Mantoux test using 5 units of freshly prepared intermediate strength PPD. Recent viral infection, immunization with live virus vaccine, or corticosteroid therapy may temporarily suppress tuberculin sensitivity. In such instances, testing should be delayed for at least 30 days. Persons known to have tuberculosis or strongly positive tuberculin tests should not be retested.

Management:

All children with positive or doubtful tests should be medically evaluated by a physician or clinic skilled in the evaluation and management of childhood tuberculosis. The evaluation should include a medical history, physical examination, chest x-ray, urinalysis, and other investigations. A careful investigation of possible sources of exposure to tuberculosis is necessary. All family members and other contacts, such as baby-sitters, should have tuberculin tests or chest x-rays. Children with doubtful reactions to the Mantoux test may be infected with atypical mycobacteria rather than the tubercle bacillus. If there is frank evidence of infection such as cervical adenopathy (enlargement of lymph nodes in the neck), appropriate biopsy may be needed to make a diagnosis. If there is a history of exposure to tuberculosis or radiographic or clinical evidence of disease compatible with tuberculosis, the child should be treated as if he had a positive reaction.

Children with doubtful reactions who have no other evidence of atypical mycobacterial infection or tuberculosis should be retested using a different skin site. If the second test is positive, the child should be treated. If the test is still doubtful, the child may be treated prophylactically for tuberculosis or retested after 3 months and then at yearly intervals.

Treatment:

All children with positive reactions should receive a course of antituberculosis medication. A child with a positive skin test and a negative chest x-ray should receive oral INH (isoniazid) daily for one year or more. Children

with clinical or radiologic evidence of tuberculosis are usually given treatment with INH and P.A.S. (para-aminosalicylic acid) for two years. Rifampin or ethambutal are used in some situations. Pyridoxine is usually given to children more than 8 years old receiving high doses of INH therapy. Children with progressive pulmonary tuberculosis, or extrapulmonary tuberculosis require skilled management in hospital situations with combinations of drugs. Household members of a patient with active tuberculosis are given INH for one year, regardless of tuberculin status.

Referral and Resources:

A child with a positive or doubtful Mantoux test should be referred to a medical resource in the community competent to manage the investigation and treatment of tuberculosis. In many situations, this will be a hospital with a medical staff experienced and competent in this field. Public health tuberculosis programs have been established in communities with high tuberculosis prevalence to provide skilled diagnostic, treatment, and follow-up services. Medication and services are usually free. Information on the availability of state and local resources may be obtained from Public Health Departments.

Counseling:

Children and their families should receive counseling on the nature of the condition, the extent of the disease in the child, and the probable outcome. The counseling should be the responsibility of the supervising physician and supporting nursing staff with follow-up by the local health aide. Children with positive tuberculin tests or primary pulmonary tuberculosis are not a source of infection to other children or adults and should not be restricted from school attendance or other activities.

Follow-up:

Children with positive tuberculin tests, doubtful tests, or active tuberculosis should be closely followed according to schedules designated by the responsible physician. Children and other persons who have had contact with a person with active tuberculosis should be tested immediately, retested in 3 to 6 weeks, then tested every 3 months or until contact with the known case has been terminated for 3 months. Routine, periodic testing is advisable in areas of high tuberculin sensitivity prevalence (more than one percent of school-age children). Follow-up should be directed by the responsible physician through the local EPSDT program, community nursing agencies, school health programs, and any organization with the capability of following children and their families.

Bacteriuria[21]

Asymptomatic urinary tract infections occur approximately 30 times more frequently in girls than in boys. Prevalence in preschool children ranges from 1 to 2%. Among first-grade children, it is 1.2% for girls and 0.4% for boys.

Diagnosis:

The diagnosis should be confirmed by cultures of three clean-voided urine specimens with colony counts on culture greater than 100,000 per ml of urine. In a child with symptoms such as burning on urination or frequent urination, two consecutive urine cultures with colony counts of 50,000 per ml or more may be sufficient for a diagnosis of urinary tract infection. Urines should be obtained so as to avoid contamination. The external genital should be carefull washed before voiding, and the urine specimen refrigerated if there is a delay in plating the culture.

Referral and Management:

A child with confirmed bacteriuria should be referred to a physician for evaluation. The physician should specifically ask for a history of bladder dysfunction such as bed wetting, frequent urination, or unexplained fevers. The physician will probably recommend treatment with sulfonamides or other antibiotics for a 10-day to 14-day period and arrange for follow-up urine cultures. Decisions about performing x-ray studies such as intravenous pyelograms, voiding cystograms, or renal function tests will be made by the physician. Children with bacteriuria resistant to therapy and children with recurrent symptomatic urinary tract infections are in greater need of these studies than children with no symptoms. Referral to a urologist may be necessary if abnormalities are detected by x-rays.

Counseling and Follow-up:

The problem of urinary tract infections should be discussed with the family by the physician. The recurrent nature of the condition should be emphasized, and the importance of follow-up cultures to ensure that the infection has been adequately treated should be stressed. Children with recurrent urinary tract infection, even those with no anatomic abnormalities of the urinary tract, are at a risk for permanent renal damage. Because follow-up

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[21]ibid., "A Guide to Screening," Chapter 18

is extremely important, mechanisms should be developed to remind families to bring the child for subsequent assessment and urine cultures. These mechanisms can be a "tickler file" in the physician's office, a systematic review system in a public health nurse's "at risk" register, or a case recall mechanism when a patient fails to keep an appointment. A neighborhood health center or local EPSDT unit with health aides would use its follow-up procedures as part of its case management responsibility.

Resources:

A child with an uncomplicated urinary tract infection can be managed by a physician in an office, with support from x-ray facilities and a laboratory to provide reliable urine cultures and sensitivities. Community support to ensure follow-up may be crucial to satisfactory management of the child. Any community agency having continuous involvement with the child or family may be able to perform this function. Examples might be local EPSDT units with health aides for case management function, social services, staff workers available for this program, schools or preschool programs, welfare departments, and community nursing agencies.

Anemia[22]

The majority of anemias detected in an EPSDT screening program are due to nutritional iron deficiency. The prevalence of iron deficiency anemia has been found to be:

Early newborn period	2-5%	
9-18 months	5-15%	
Adolescent females	5-15%	(A smaller proportion of adolescent males develop significant iron deficiency anemia.)

Prevalence of other anemias is approximately 0.1% to 0.3% in children. These anemias comprise mainly sickle cell anemia and other chronic anemias.

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[22]ibid., "A Guide to Screening," Chapter 19

Diagnosis:

Normal values for hematocrit and hemoglobin are shown in the following table:

Age	*Hematocrit %*	Hemoglobin *gm/100 ml*
2-5 days	45 or higher	15 or higher
2 months - 2 years	33 or higher	11 or higher
2 years - 10 years	36 or higher	12 or higher
>10 years	38 or higher	13 or higher

The tests should be repeated if values below those regarded as normal for age are obtained.

In obtaining blood for hemoglobin or hematocrit determination, the skin site must be cleaned and warm when obtaining blood by finger or heel prick. A free flow of blood should be obtained because squeezing or "milking" dilutes the blood sample with tissue fluid giving a falsely low result.

A presumptive diagnosis of nutritional iron deficiency anemia may be made on the basis of a low hematocrit or hemoglobin level and a history suggestive of inadequate iron intake. Infants 16 to 18 months old with nutritional anemia almost always have a history of excessive milk intake. A child less than 6 months old is less likely to have anemia from an iron deficient diet; therefore, other causes should be investigated.

A child with anemia should be seen by a physician and evaluated to determine if further studies are needed or if treatment with an oral iron supplement should be initiated.

Stool studies for ova, parasites, and occult blood should be performed if history suggests parasitic infection or gastrointestinal blood loss. Children with anemia and a positive sickle test should be studied for sickle cell disease.

Treatment:

A therapeutic trial of oral ferrous sulphate, 2 mg/kg three times daily for 3 months should be given to a child with presumed nutritional iron deficiency anemia. Attention to diet by reduction of milk intake and addition of iron-containing foods (eggs, meat, and cereal) is essential. The hematocrit or hemoglobin should be checked in 4 to 6 weeks.

A child who does not improve on an oral iron supplement should be evaluated to determine whether the medication was administered. If anemia

persists despite an adequate intake of an iron supplement, restriction of milk intake, and a reasonable intake of iron-containing foods, the child should be thoroughly evaluated for other causes of anemia by further studies.

Referral:

A child with a severe degree of anemia, or a child not responding to an iron supplement, should be referred to a physician or hospital competent to carry out further investigations and treatment.

Counseling and Follow-up:

Counseling and follow-up of children with treated iron deficiency anemia is a long-term process. Dietary advice should be accompanied by home visits from nurses or health aides to reinforce recommendations and to explain the recommended changes in family food buying and preparation, and to provide other nutrition education.

Resources:

Medical resources for further evaluation and treatment of children with severe anemias might be a community hospital or the pediatric hematology department of a referral center.

Community resources for supervising and counseling families would include EPSDT health aides, public health and visiting nurses programs, and nutrition programs with dietary counselors.

Sickle Cell Disease and Trait[23]

Approximately 8% of Afro-Americans have the sickle cell trait, and one in 400 has sickle cell disease. A much smaller percentage of the disease occurs in persons of Latin-American origin.

Diagnosis:

A positive sickle cell test performed using the sickle cell preparation (sodium metabisulphite) or by the sickledex method should be followed by a

[23]Ibid., "A Guide to Screening," Chapter 20

hemoglobin electrophoresis. The latter test distinguishes sickle cell trait from sickle cell disease and from other abnormal hemoglobin conditions. These tests are used in children 9 months or older. They are unreliable in a younger child because the tests depend on the presence of hemoglobin S, which is temporarily replaced by fetal hemoglobin (HbF) in younger infants. Diagnosis in the newborn or young infant may be made by the cellulose acetate electrophoresis method. Prenatal diagnosis of sickle cell disease by intra-uterine sampling of fetal blood is a future possibility.

Management:

Children with *sickle cell trait* usually will live completely normal lives. Health professionals who detect a child or adult with sickle cell trait are responsible for providing careful, specific, and sensitive information about the condition. Explanations should be repeated and supported with written materials whenever possible and appropriate. All family members should be tested when one member has a positive sickle test. Advice may be offered to adults by explaining the potential risks of bearing children who may inherit the sickle factor. A pregnant woman with sickle trait represents a special problem. If the father has sickle trait, the newborn infant has a one-in-four chance of having sickle cell disease. The options open to an individual with sickle cell trait are:

- avoiding marriage to persons with the trait,
- avoiding all pregnancies through birth control if both partners have the trait,
- terminating any unplanned pregnancy early through legal abortion if both partners have the trait,
- initiating pregnancy through artificial insemination,
- running a 25% risk of producing a child affected by a sickle cell disease if both partners have the trait.

In view of these considerations, it seems reasonable to restrict screening for sickle cell trait to young adults.

A child with *sickle cell disease* should be referred to a source of competent medical care equipped to deal with the severe and sometimes life-threatening episodes of sickle crises. The nature of the disease should be explained to the family, and the importance of close and continuous health supervision stressed. The family should be instructed to seek immediate medical help if the child has fever, infection, or weakness. Referral to a hospital or pediatric referral center is advisable in these circumstances.

Counseling and Follow-up:

Explaining the problems of sickle cell disease and trait can be difficult. Well trained counselors who may be nurses or community aides may allay needless anxiety. Families with sickle cell problems frequently need sustained support, particularly if a family member has sickle cell disease. Problems of transportation to medical care, repeated hospitalization, interrupted schooling, and depression need to be faced and solved. Families need help to cope with the fact that a child with sickle cell disease has a shortened life expectancy. A child with sickle cell disease needs careful and continous follow-up by a physician and supportive personnel in addition to access to a referral center for management of complications of the disease.

Resources:

Children of school age handicapped by sickle cell disease may qualify for education services through the State Department of Special Education. In many states, organizations such as the Sickle Cell Foundation[24] are active in educational and supportive services for families with sickle cell disease.

Increased Lead Absorption[25]

In the United States, 2.5 million children 1 through 5 years of age are at risk of undue lead absorption. Approximately 600,000 will be affected by the disease, generally as a result of living in old, deteriorated housing containing lead-based paint. Prevalence is lower in suburban areas and may be extremely low in areas with houses built after the 1950's and with little exposure to industrial sources of lead. Classical symptomatic lead poisoning is generally not seen. Approximately 6,000 will develop neurologic damage including slow learning, hyperactivity, and behavioral disorders even though the child is asymptomatic.

Diagnosis:

All children 1 through 5 years of age should receive an ertyhrocyte protoporphyrin test. If the results are 60 μg/dl or more, the child should receive

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[24]Contact the National Association for Sickle Cell Disease, Inc., 945 South Western Avenue, Suite 206, Los Angeles, California 90006. Telephone: 213-731-1166.

[25]op. cit., "A Guide to Screening," Chapter 21

a blood lead test. If the blood lead is less than 30 μg/dl, the child should receive a hematologic evaluation to determine if the child is iron deficient or suffering from another porphyria. However, if the blood lead is 30 μg/dl or more, the child should be considered to have undue lead absorption. Both the erytythrocyte protoporphyrin and blood lead tests can be performed readily on a finger prick sample. In view of the known difficulty in carrying out blood lead level determinations, only experienced, proficient laboratories should utilized.

Referral:

Children Identified with undue lead absorption should be referred to resources especially equipped to evaluate and treat the condition. Physicians accepting these referrals should have experience with the management of undue lead absorption and must have access to reliable laboratory and hospital facilities.

Management:

The physician to whom the child is referred will probably undertake the following steps:

1. Clinical evaluation for symptoms and signs of lead intoxication

2. Additional laboratory studies for evidence of lead intoxication

3. X-ray studies for evidence of lead lines in the long bones and radio-opaque material in the gastrointestinal tract

4. Treatment, if indicated, by chelation using CaEDTA (calcium disodium versenate) or BAL (2,3-dimercaptopropanol) under close medical supervision in the hospital. The physician supervising the care of the child may determine that a mild lead intoxication could be followed on an outpatient basis

5. Notification of the appropriate community agency (e.g., public health department, housing authority, etc.) to initiate environmental lead hazard identification and reduction services to protect the child from additional exposure

6. Testing of other family or household members for undue lead absorption

7. Arrangement for continued pediatric follow-up

Counseling:

Families with children who have undue lead absorption need counseling to help them understand the nature of the threat of lead poisoning to a child's health or life. They need help in following medical recommendations and assistance in making their houses safe from the hazard of lead-based paint. They may need advice and support in dealing with landlords. On occasion, they may need help in finding a different home that is free of lead-based paint hazards. These at-risk children should have priority for day care or preschool programs, particularly if they manifest severe pica (a tendency to indiscriminately ingest nonfood substances).

Follow-up:

A child with undue lead absorption is at risk of future developmental and intellectual handicaps. Follow-up is important to monitor the response to treatment and to detect relapses by obtaining periodic blood samples for erythrocyte protoporphyrin and blood lead testing. Good comprehensive care is also essential so early special educational services can be obtained if necessary. Follow-through for housing rehabilitation or relocation is essential. Recurrence of poisoning is an indictment of failure of the whole effort.

Resources:

The high prevalence areas present problems which are best handled by the community-wide approach. Many cities have formed Childhood Lead Poisoning Prevention Programs which bring together resources, such as education, housing inspection and lead hazard reduction services, legal services, screening, referral centers and hospitals, and community or State laboratory services.

In communities without intensive lead poisoning prevention programs, it may be necessary to establish such a program. Close coordination is required with the State and local Departments of Public Health. These departments can provide invaluable advice and assistance.

APPENDIX

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

LOCATION OF REGIONAL OFFICES AND BOUNDRIES OF JURISDICTION

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